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ABSTRACT

This paper discuses the findings of a research study that compared 191 families of children with spina bifida and 145 families of children with mental retardation. Findings include: (1) mothers of children with developmental disabilities (DD) perceived that they experienced more poor health/mood problems than the mothers of children with Spina Bifida; (2) mothers of children with DD perceived that they worried more about their children than the mothers of children with spina bifida; (3) mothers of children with DD perceived that they experienced more problems due to low integration of the child with the disability into the family; (4) mothers of children with DD perceived that their sons and daughters have more personality and behavior problems than the mothers of children with spina bifida; and (5) mothers of children with spina bifida perceived that their children have more problems in the area of self-care than the mothers of children with DD. The paper identifies the following strategies for collaborating with families: maintain confidentiality, provide emotional support in a non-judgmental way, recognize that parenting is a specialized discipline, provide open and accurate information about normal development and necessary services, and make meaningful attempts to involve parents. (CR)

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Families of Children with Mental Retardation: Effective Collaboration

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Families of Children with Mental Retardation: Effective Collaboration

A comprehensive review of literature shows that families of children with mental retardation have attracted considerable research attention. The body of research literature that has focused on the impact of an individual with mental retardation on the family indicates that parents go through psychological stages for adaptation and acceptance. Families encounter stress and families' development through stages of life cycle is arrested. And, according to Turnbull's theory of Family Systems, the siblings and the extended family members also get affected. Poznanski reported that psychiatrists treat more siblings of disabled children than disabled children themselves.

This paper has two main purposes: (1) to report the findings of a research study that compared the effects of mental retardation and spina bifida (myelomeningocele), a physical disability on family functioning; and (2) to list some strategies that have been effective in collaborating with families of children who have mental retardation. Spina bifida is a cogential deformity of the central nervous system. It results in multiple challenges such as paralysis below the lesion, double incontinence, and hydrocephalus (Mitchell, Fiewell & Davy, 1983). Specifically, the study addressed the following questions:

1. Do mothers of children with developmental disabilities (DD) perceive that they experience more health/mood problems when compared with mothers of children with spina bifida (SB)?

2. Do mothers of children with developmental disabilities perceive that they experience attitude towards their child, which is more negative when compared with the attitude of mothers of children with spina bifida?
3. Do mothers of children with developmental disabilities perceive that their families are experiencing problems due to low family integration when compared with mothers of children with spina bifida?
4. Do mothers of children with developmental disabilities think that their disabled children have more personality and behavior problems when compared with mothers of children with spina bifida?
5. Do mothers of children with developmental disabilities perceive that their disabled child has more problems in the area of self-care when compared with mothers of children with spina bifida?

Research Methods

This section describes the setting, subjects, instrumentation, and data collection procedures. Each one is covered under a separate heading.

Setting

The study was carried out in Pennsylvania, in cooperation with the Rehabilitation Institute of Pittsburgh and Spina Bifida Association of Greater Pittsburgh, affiliated with Children's Hospital of Pittsburgh. Both of these health care agencies serve children with various disabilities and their families.

Subjects

The sample (N=191) for this study constituted of mothers of children with spina bifida who were served either at Children's Hospital of Pittsburgh or the Rehabilitation

Institute of Pittsburgh. The participants of the study met the following criteria: (1) they were natural mothers of a child who had spina bifida only and did not have mental retardation; (2) the child was between the ages of 1-21 years; (3) their child with spina bifida lived with them; and (4) that they were Caucasians.

Instruments

The Questionnaire on Resources and Stress (QRS) was selected for use in the present study. The QRS is a self-administered, 285-item true-false instrument developed by Holroyd (1984, 1987) to measure the impact of illness or disability on family members. The QRS measures the level of stress in families who are caring for ill or disabled relatives. The QRS scores yield a family profile which can be used to identify different needs of families. For the purpose of this study, the normative data for the families of developmentally disabled children that are reported in the QRS manual were used for comparative reasons.

As shown in Table 1, the QRS has 15 scales that assess 15 variables pertinent to families of ill or disabled children. Each of the 15 scales yields a score, which can be summed to arrive at a total score. Elevated scores on any of the scales indicate areas of concerns and low scores reflect strengths.

Table 1

Variables Assessed by the QRS

Scales	Problems Experienced by the Family as a Whole
1. Poor Health/Mood	Respondent's sadness, depression, & fatigue
2. Excess Time Demands	Concern about inability to get out of home often
3. Negative Attitude	Respondent's excessive worrying about the child
4. Overprotection/Dependency	Problems resulting from child's dependency
5. Lack of Social Support	Shortage of supportive resources
6. Overcommitment	Respondent's absorbed involvement
7. Pessimism	Respondent's fear about future
8. Lack of Family Integration	Family disharmony and lack of intrafamilial support
9. Limits on Family Opportunity	Family members forgo opportunities for jobs etc.
10. Financial Problems	Excess cost of care and inadequacy of income
11. Physical Incapacitation	Disabled child's problems in personal care taking
12. Lack of Activities	Not enough activities to keep the child busy
13. Occupational Limitations	Respondent's concern about child's employability
14. Social Obtrusiveness	Concern about child's appearance and behavior
15. Difficult Personality	Respondent's perception about child's personality

The QRS was chosen for the study because of its relevance for the research questions and its technical adequacy. Holroyd (1987) reported the commendably high, overall Kuder-Richardson internal consistency of .96. Also the reliability for all of the 15 scales with the exception of four (Lack of Social Support, Social obtrusiveness, Occupational Limitations for Index Case, and Overcommitment/Martyrdom) is moderately high. It ranges from . 61 to .88.

The validity of the QRS is reported in its manual. QRS was validated by research on families of disabled and ill children. Three types of studies were done for establishing its validity: content, criterion, and construct (Holroyd, 1987).

The norms of QRS are based on parents of 107 "normal children" and 329 families of children with mental disabilities, psychiatric problems, cerebral palsy, and medical illnesses (Holroyd, 1987).

Demographic Questionnaire

In order to ascertain the demographic characteristics of the sample, a demographic questionnaire was developed by the investigator. The questionnaire had eight items dealing with respondent's age, marital status, occupation, educational level, number of children, age/sex of the child with spina bifida, and spouse's occupation.

Procedures

The names, addresses, and motherhood (natural vs. adoptive) of the subjects and other pertinent data were obtained from the record files of the Spina Bifida Association of Greater Pittsburgh, Children's Hospital of Pittsburgh, and the Rehabilitation Institute of Pittsburgh. The information on the index child's cognitive status (mental retardation vs.

normal intelligence) was also determined from these sources. Ethical standards were complied with during all phases of data collection.

After the selection of subjects according to the specified criteria, 334 mothers were sent a cover letter; Questionnaire on Resources and Stress, a Demographic Questionnaire, and a stamped, preaddressed return envelope.

Approximately three weeks after the initial mailing, a postcard was sent to each member of the sample. It served as a thank you note for those who had responded and a gentle reminder for those who had not.

Approximately two weeks after the first follow up, a letter was sent to those whose responses had not yet arrived. The follow-ups were sent to increase the response rate. The data collection lasted for approximately 11 weeks. A few of the envelopes were returned by the post office. The final response rate was 60.4%.

Results

The analysis of demographic data indicated that majority of the sample families had two parents. Approximately half the mothers worked outside the house. Most of the fathers were skilled employees such as mechanics, millwrights, fitters, and electricians. A large proportion of the families had two children. And the gender of the referent child represented half males and half females. The mean age of the mothers in the sample was 38 years. And, the mean age of a child with spina bifida was 10.29 years (SD = 4.18).

To address the research questions, the scores obtained by mothers of children with spina bifida (SB) on five scales of QRS were compared with the norm scores of the mothers of developmentally disabled (DD) children as reported in the QRS manual. The comparisons were accomplished by computing the means and the standard deviations.

Table 2 shows that on the Poor Health/Mood Scale of the QRS, the mean score of mothers of developmentally disabled children is higher (M=4.99, SD=3.02) than the mean score of mothers of children with spina bifida (M=3.68, SD=3.21). The results of a t-test for independent samples confirm that the difference between the two group means is significant (t=-3.79, df=334, p> .05), suggesting that the mothers of children with developmental disabilities perceive that they experience more poor health/mood problems than the mothers of children with spina bifida.

Table 2

Poor Health/Mood Scale-SB Group and DD Group

Group	M	SD	t	P
SB (N=191)	3.68	3.21		
			-3.79	<.05
DD (N=145)	4.99	3.02		

As shown in Table 3, on the Negative Attitude Scale of the QRS, mothers of children with developmental disabilities scored higher (M=11.08, SD=4.56) than the mothers of children with spina bifida (M=7.15, SD=3.62). The results of a t-test confirm that the mothers of children with developmental disabilities perceive that they worry more about their children than the mothers of children with spina bifida.

Table 3

Negative attitude Scale-SB Group and DD Group

Group	M	SD	t	P
SB (N=191)	7.51	3.62		
			-2.93	<.05
DD (N=145)	11.08	4.56		

As shown in Table 4, the comparison of mothers of children with spina bifida with the mothers of children with developmental disabilities on the Lack of Family Integration Scale revealed that the scores of mothers of children with developmental disabilities are higher (M=5.34, SD=3.82) than the mothers of children with spina bifida (M=3.19, SD=2.74). A t-test for independent samples was applied to determine if the difference between the two groups is significant. The t-test yielded a value of –4.88. This value is significant at the .05 level. These results suggest that the mothers of children with developmental disabilities perceive that they experience more problems due to low integration of the disabled child in the family than the mothers of children with spina bifida

Table 4

Lack of Family Integration Scale – SB Group and DD Group

Group	M	SD	t	P
SB (N=191)	3.19	2.74		
			-4.88	<.05
DD (N=145)	5.34	3.82		

As shown in Table 5, the comparison of the mothers of children with spina bifida and mothers of children with developmental disabilities revealed that there are significant differences between the two on the Difficult Personality Scale of QRS. These results suggest that the mothers of children with developmental disabilities perceive that their sons and daughters have more personality and behavior problems than the mothers of children with spina bifida.

Table 5

Difficult Personality Scale – SB Group and DD Group

Group	M	SD	t	P
SB (N=191)	6.76	4.59	-2.25	<.05
DD (N=145)	15.37	5.47		

As shown in Table 6, the comparison of Physical Incapacitation scores indicate that the scores of mothers of children with spina bifida are higher than those of mothers of children with developmental disabilities. The results of a t-test for independent samples confirm that there are significant differences between the two groups. This means that mothers of children with spina bifida perceive that their children have more problems in the area of self-care than the mothers of children with developmental disabilities. This is the only scale where mothers of children with spina bifida scored higher than the mothers of children with developmental disabilities.

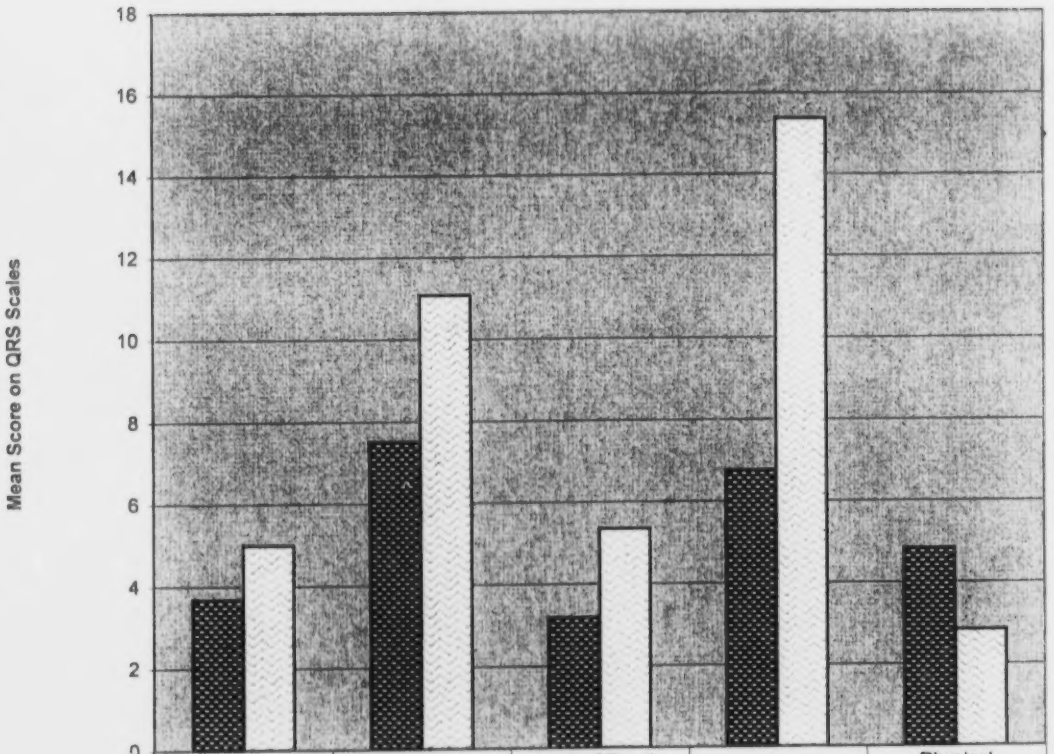
Table 6

Physical Incapacitation Scale – SB Group and DD Group

Group	M	SD	t	P
SB (N=191)	4.83	2.37		
			5.00	<.05
DD (N=145)	2.83	2.07		

To summarize, the findings of the present study suggest that as perceived by mothers of children with developmental disabilities (DD), a child with developmental disability has more negative effects on the family than a child with spina bifida. As shown in Figure 1, these effects are experienced by the family in the form of: Poor maternal health/mood, negative attitude towards the child, lack of family integration, and maternal perceptional that child with developmental disability is difficult.

Figure 1. Summary of Findings



	Poor Health Mood	Negative Attittude	Lack of Family Integration	Difficult Personality	Physical Incapacitation
SB Group	3.68	7.51	3.19	6.76	4.83
DD Group	4.99	11.08	5.34	15.37	2.83

Scales of QRS

Limitations of the Study

The findings of this study should be interpreted with caution because of the following reasons. First, the test-retest reliability of the QRS is not known. This means that the extent to which QRS scores are consistent and stable overtime is unclear. Second, the non-respondents may have differed from the respondents in significant ways. For example, the non-respondents may have felt hesitant in revealing their feelings. Third, the effects of a child's disability are based on maternal perceptions. Maternal perceptions are important, but do not necessarily reflect family realities. And finally, the mothers of children with spina bifida represent Pennsylvania citizens. Because of various geographical influences, the study group may differ from the populations of other geographical regions.

Despite some of the caveats mentioned, the present investigation is unique in that it has examined the impact of childhood disability on the family with a large sample. There is no doubt that families of children with mental retardation are under considerable stress. Therefore, professionals working with families are encouraged to support these undaunted members of our society in appropriate ways. An informed professional can be a catalyst of families' positive thinking. And, as Turnbull & Turnbull (2001) have maintained, positive thinking can be the springboard for energy and great expectations. Listed below are the strategies that are effective in collaborating with families:

- ✓ Professionals should maintain confidentiality for establishing trust and building healthy working relationship (Wasik, Bryant, & Lyon, 1990)

- ✓ Professionals need to provide emotional support in non-judgmental way. Some professionals have more negative view of families than families have of themselves (Seligman, 1991).
- ✓ Professionals need to recognize that parenting is a specialized discipline and that parents bring values, beliefs, and powerful assets of their own to the care of child (Beckman, 1991; Turnbull & Turnbull, 2001)
- ✓ Parents generally appreciate open/accurate information about normal development and necessary services available in the community (Beckman, 199; Lyon & Lyon, 1991)
- ✓ Professional ought to make sincere and meaningful attempts to involve parents in decision making beyond what is minimally required by law.
- ✓ Professionals ought to acknowledge that the family is a system, with its own unique structure functions, and life cycle (Turnbull & Turnbull, 2001).

Note: The terms mental retardation and developmental disability have been used interchangeably in this manuscript,

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